CNRC
CLINICAL NEUROGENOMICS RESEARCH CENTER

UCLA Health

You are invited to participate in a research study.

Purpose of this study:

To identify and understand the genetic basis of neurological diseases.

What are the genetic causes of neurological disorders?

Neurological disorders affect the brain, spinal cord, and nerves and can cause problems including difficulties with moving, speaking, swallowing, breathing, learning, memory, and behavior. Some examples of neurological disorders include dementia, epilepsy, neuropathy, stroke, or movement disorders. In some cases, these disorders can be caused by changes (also called mutations) in segments of DNA, known as the genes. Although we know of hundreds of genes that can cause neurological disease, many still need to be discovered.

Who is eligible?

Anyone interested is welcome to participate. Even if you don't have a neurological disorder your DNA may help us better understand diseases in others.

What is involved in participation?

1. If you are participating in the Precision Health Initiative, the sample they collect will be shared with us. You may also be asked to provide a saliva sample by spitting into a small collection tube.
2. You may be asked to have 1-2 tablespoons of blood drawn. In very rare cases have a small punch skin or muscle biopsy performed, urine, stool, or tears collected, or a lumbar puncture to obtain spinal fluid. The total time for each of these procedures will be less than 30 minutes. In some cases you may be asked to do questionnaires or clinical assessments to help determine phenotype. These may take an additional 5-10 minutes each.
3. We may need access to your UCLA Health medical records to determine your neurological symptoms, so you will be asked to sign a permission form to use your personal health information for research.
4. If any clinically relevant genetic results are discovered during the course of this research, you will have the choice of whether or not you would like to know about them and speak to a certified genetic counselor and/or physician.

Potential risks and discomforts?

Occasionally one or more of the following potential side effects of taking blood or skin samples may occur: pain, bruising, slight bleeding, light-headedness, fainting and (rarely) an infection. A trained technician will be drawing the blood. If a muscle biopsy, skin biopsy, or spinal fluid is to be obtained, a trained physician will perform this under local anesthesia. You may get tired or bored when we are asking you questions or you are completing questionnaires. You do not have to answer any question you do not want to answer.

There are potential psychological risks associated with the return of genetic test results. Because genes are shared with blood relatives, the findings may impact or have unintended consequences on family or other relationships.

You will have the opportunity to discuss these potential risks and discomforts with a member of the study team and/or a genetic counselor during the consent process.

Anticipated benefits to subjects and society:

One potential direct benefit to you may be the determination of the genetic cause of your neurological symptoms but we cannot guarantee anything will be found during the course of this research. A potential benefit to society is an increased understanding of genetic diseases which affect the brain.

Where can I get more information on the study? If you or a family member would like more information or would like to participate, please visit our website at https://www.uclahealth.org/neurology/cnrc or contact a study coordinator at (310) 825-2320. To complete the electronic consent, visit https://unc.dgit.ucla.edu/cnrc or scan the QR code.